



THE UNIVERSITY OF
MAINE

Maine Autism Institute for
Education and Research

Pathways

Summer 2021

The **Maine Autism Institute for Education and Research** (MAIER) is a partnership between the University of Maine College of Education and Human Development and the Maine Department of Education.

MAIER is dedicated to building state-wide capacity to improve outcomes for individuals with autism spectrum disorder (ASD).

- Leadership
- Training
- Professional Development
- Technical Assistance
- Consultation
- Research

Upcoming Events

Maine Early Childhood Education Conference 2021

Cross Center, Bangor.
October 22nd & 23rd

Join early childhood professionals from around the state for this two-day conference featuring sessions focused on best practices in early childhood education including: early learning, social and emotional skills, leadership, equity and diversity, policy, meeting the needs of diverse learners, and more! For more information, visit the [ECE Conference 2021 webpage](https://www.maineaeyc.org/events) ([maineaeyc.org/events](https://www.maineaeyc.org/events))

Greetings from the Maine Autism Institute for Education and Research,

As summer 2021 draws to a close and we turn our attention to the new academic year, it seems much has changed, yet many challenges still lay ahead. While our lives, schools, and workplaces may be safer than they were a year ago thanks to the availability of vaccines and safety measures, we are still confronted with the need and desire to keep our community safe during the continued pandemic.



Much of our work here at MAIER is founded on our face-to-face trainings and workshops for educators and professionals and our interactions with families and caregivers at community events and MAIER family outings. We miss these conversations and interactions that keep us grounded in our mission as we continue to offer and develop new ways to meet those objectives. While we had hopes we would enter this new academic year by again offering on-site professional trainings and family educational and recreational events, at this time we will continue our offerings virtual and online only. We will keep you posted of any changes as they occur. Meanwhile, we offer this end of summer issue of *Pathways*, with our latest news and information to keep you abreast of our work and resources that continue to be available from MAIER.

You can help us by sharing this newsletter with others interested in MAIER's work or offerings. Please do not hesitate to reach out to us if we can be of assistance. Contact us by [email](mailto:maineautisminstitute@maine.edu) (maineautisminstitute@maine.edu) or phone (207-581-2352)

Best wishes for the upcoming fall season,
Deborah L. Rooks-Ellis, Ph.D., Director,
Donna Doherty, MAIER Family Partnership Director
Maine Autism Institute for Education and Research

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The Maine Department of Education provides significant support and funding for the activities and outreach of the Maine Autism Institute for Education and Research.

NEWS & ANNOUNCEMENTS

MAIER Receives Grant to Support Peer Education in Rural Schools

The **Maine Autism Institute for Education and Research (MAIER)** has received a \$4,854 grant from the Organization for Autism Research to support a peer education project that aims to increase autism acceptance among students in grades K-8. Sarah Howorth, assistant professor of special education and coordinator of the graduate program in special education, says the grant will allow MAIER to distribute autism awareness and education kits to 12 rural school districts in Maine, beginning in September 2021. Materials and resources for educators and families will also be posted to [MAIER's website](http://umaine.edu/autisminstitute/). (umaine.edu/autisminstitute/)

“Autos for Autism” Fundraiser Supports MAIER Family Partnership

Throughout *Autism Awareness and Acceptance* month this past April, the Mid-Coast Business Development Group (Mid-Coast BDG), a group of automotive service and repair shops in Midcoast Maine, and many Maine NAPA stores joined together to support the work of MAIER and help raise autism awareness and acceptance in their communities through an “Autos for Autism” fundraiser. Despite the unprecedented challenges faced by most businesses this past year, participating shops posted flyers and shared information with their customers about autism awareness and about the mission and work of MAIER. Businesses solicited donations from their customers to support our ongoing activities to serve Maine families affected by autism.

Thanks to the enthusiasm and determination of Meg Lewis, VP of the Mid-Coast Business Development Group, “Autos for Autism 2021” fundraiser raised over \$3600! When delivering the news of their fundraising efforts, Meg wrote, “We are thrilled that we had such a success with our fundraising efforts this year and are looking forward to doing even better next year!” As an annual event for the third year running, their donations will continue to support MAIER family partnership activities and resources. We look forward to resuming our in-person family events in the near future, and the generosity of the Mid-Coast BDG and their customers will go a long way toward making this possible.

Our sincere thanks go out to the Mid-Coast BDG and NAPA dealers who participated in this fundraiser and to their many customers who generously donated to help support MAIER’s outreach to Maine families affected by autism.



Fundraisers help support MAIER Family Partnership activities such as the “Outdoor Adventure Day” at the Adaptive Outdoor Education Center in 2019.



“We are thrilled that we had such a success with our fundraising this year and are looking forward to doing even better next year!”

~Meg Lewis,

VP Mid-Coast Business Development Group

MAIER's 2020-21 PD sessions and archived workshops are still available for viewing and contact hours!

Visit the [MAIER PD webpage](http://umaine.edu/autisminstitute/trainings/) (umaine.edu/autisminstitute/trainings/) for listings of all the available workshops, webinars and training modules.



Ongoing Professional Development Opportunities


Here at MAIER we have been overwhelmed by the dedication of all those who participated in our 2020-21 professional development opportunities this year. While we adapted our PD offerings to an online modality to meet the current safety requirements, educators, professionals, and para-professionals from across the state (and in some cases, across the U.S. and outside the U.S.) took advantage of our webinars and online training modules in unprecedented numbers. We are pleased to have engaged with so many of you through our online trainings.

While we continue to plan our new offerings for the upcoming year, we will continue to offer our 2020-21 PD through this fall, along with many of our archived workshops from previous years. If you missed any of these sessions, or want to refresh your memory for the upcoming year, check out our MAIER PD webpage for listings of all the available workshops, webinars and training modules. Sessions are free for viewing and confer education contact hours upon completion. Visit [MAIER's PD webpage](http://umaine.edu/autisminstitute/trainings/) (umaine.edu/autisminstitute/trainings/) today!



Invitation to participate in PEERS® research study

Drs. Sarah Howorth and Libby Stone-Sterling are currently recruiting teens and young adults for participation in a research study to investigate the delivery of the PEERS® interpersonal skills curriculum via Zoom. Eligible participants will be Vocational Rehab clients who are between the ages of 14- 24 years, have an ASD diagnosis as part of their educational record, and are interested in improving their interpersonal skills. Adult participants will have the consent of a guardian or caregiver to participate in the study. For full information about participating, including contact information if you are interested in participating, visit [PEERS 2021 Research Study invitation here](http://umaine.edu/autisminstitute/pathways/summer-2021/peers-research-invitation-2021/). (umaine.edu/autisminstitute/pathways/summer-2021/peers-research-invitation-2021/)



AUTISM RESEARCH

AN INTRODUCTION

It is not that long ago when there was very little understanding about autism and even less was known about the effectiveness of treatments and interventions. Today, parents and caregivers can be overwhelmed by information in print, on TV, online, and in social media. Educators, professionals, family members, friends, and other parents and caregivers offer additional sources of news and information about how to best help your family member on the autism spectrum. Knowing how to sort through all this information can be both confusing and exhausting. However, being a knowledgeable consumer can help you advocate for services and supports that have scientific evidence of their effectiveness and make the best use of your time, efforts, and mental and financial resources.

Here at the Maine Autism Institute for Education and Research (MAIER), we support evidence-based practices and research supported information in serving individuals and families impacted by autism and the professionals who serve them. In this article, we will provide an overview of the importance of autism research to further our understanding of autism, the types of research you may encounter, and the impact of research findings on individuals and families. In addition, we offer suggestions as to how you can evaluate autism information and research, and offer resources for further reading if desired.

Researchers who conduct studies to better understand autism have worked diligently to improve the lives of individuals on the spectrum and their families. Scientists have studied the causes and characteristics of autism, its impact on individuals at different points in their development, the impact of autism on family life and relationships, and the effectiveness of treatments and interventions. Other scientists are studying the genetics of autism, its connections to other medical or behavioral conditions, or assessment tools. While autism research in these and other areas are all important, we will focus on two examples to illustrate the research process.

Many autism researchers focus on finding effective treatments and interventions and these studies are conducted under strict conditions by a trained research team. Intervention studies require adherence to specific rules for how individuals are chosen to participate (“recruited”), how the interventions are carried out (“implemented”), how the effects are measured and recorded (“data”), and how the data are analyzed to determine the effect, if any. Research studies must be reviewed by other experts in the field (“peer-reviewed”) to assure that the research was conducted ethically, used sound scientific principles and procedures, and that the results and conclusions accurately reflect the findings.

These research studies most often are conducted at major medical centers, universities, and research centers and have been integral to our knowledge of which interventions and treatments are effective for individuals on the autism spectrum, called evidence-based practices (EBP). According to the National Professional Development Center on Autism Spectrum Disorder, “An evidence-based practice is an instructional/intervention procedure or set of procedures for which researchers have provided an acceptable level of research that shows the practice produces positive outcomes for children, youth, and/or adults with ASD.” While not all treatments and interventions are equally effective for all individuals on the spectrum, professionals draw on EBPs to develop and implement education and treatment plans on an individual basis.

Other autism research may study the impact of ASD on family life, communication and relationships between individuals and families and their medical or education professionals, and peer or intimate relationship experiences, perceptions, and outcomes for persons with ASD. These studies may use surveys, interviews, observations, or focus groups to gather data directly from individuals with autism or their close family or peers, and analyze the data to help better understand the experiences of living with autism. These researchers use specific scientific principles to conduct their studies, to analyze the data, and to report findings. These research studies must also be reviewed by other experts in the field and replicated in further

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studies to support the conclusions. This type of research is important to advance our understanding of the day-to-day lives of those on the spectrum and their families, and design supports and resources for day-to-day living.

While this may all seem complicated to those who are not researchers, most education, medical, and behavioral professionals are trained to identify and study peer-reviewed research and base their treatment and intervention recommendations on evidence-based practices and research-supported conclusions. As an individual with ASD or a parent or caregiver, you have the right to question your providers about the research and recommended treatments and to explore the research yourself. While published research articles are often complex and written in scientific jargon, there are ways you can explore research to learn more from their original sources.

The *Autism Research Institute* (ARI) and the *Organization for Autism Research* (OAR) are two organizations that provide resources to help individuals, parents, and caregivers in sorting through the media and research that bombards us daily to find information that is reliable and based on sound research findings. (See the reference list at the end of this article to download these free resources.)

ARI and OAR offer the following suggestions:

- Be an informed consumer: Evaluate your own family member's needs as well the research. Consider what is appropriate for your child, teen, or adult family member with ASD, or for yourself if you are a self-advocate.
- Gather information from a variety of sources, network with other parents/caregivers, and talk with your education and medical professionals to identify useful sources of information.
- Remember that sound autism research is based on three principals:
 - * It uses scientific principles,
 - * It has been peer reviewed, and
 - * The study can be replicated.
- Ask yourself the following questions to assess what you are hearing or reading:
 - * What is the source?
 - * Who conducted the research?
 - * Who funded the research?
 - * Was this research peer-reviewed?
 - * Has this research been replicated?
 - * What other studies are referred to in this report?

The OAR (2019) reminds all of us to “Beware of those who claim to have a cure,” as not all treatments and interventions that are promoted in the media are supported by sound research. Your hopes and dreams for yourself, if you are an individual on the spectrum, and/or for your family member with ASD “may leave you vulnerable to those marketing a variety of educational, medical, and other alternative treatments for autism that have no proof of effectiveness.” However, being a cautious consumer will leave you “better equipped to ask the right questions of your child’s doctors, therapists, and teachers about specific interventions or treatment options.” (OAR, 2019)

In a recent webinar, “*Autism Research: Nothing about me without me*,” Wenn Lawson, Ph.D., an autism self-advocate, described “Participatory Research,” another type of research that bears noting for the autism community. This type of research includes participants (in this case, persons on the autism spectrum) in all stages of the research project, including what topics will be studied. He described the process as a “co-



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production” in which the individuals with autism are part of the research team from the initial stages to the end. Accommodations are built into the research plan from the very beginning to assure persons on the spectrum are active research partners. While participatory research takes time and attention to individual accommodations, this type of research holds promise for truly inclusive research that provides a voice to individuals on the spectrum. In addition, it can lead to new insights and appreciation of those in the autism community while empowering them as valuable partners in the research process. For more information on Dr. Lawson’s webinar, see our reference list at the end of this article.

In closing, I would like to encourage you and your family members to be open to opportunities to participate in autism research when you qualify to participate and when you are able. Before agreeing, be sure to ask the questions we have discussed in this article to assure your rights are being protected and the project or investigation is based on sound scientific principles. Before you agree to participate, researchers are required to provide you with informed consent that includes your full understanding of what you are being asked to do, the potential risks and benefits, and how the results will be used. As a community, we have much to gain from autism research, and your willingness as individuals and families impacted by ASD to participate in ongoing and new research is vital to this work.

References

Autism Research Institute. (2021, July 14). *Guide to Identifying and Understanding Scientific Research about Autism*. <https://www.autism.org/a-guide-to-identifying-and-understanding-good-scientific-research-about-autism/>

The National Professional Development Center on Autism Spectrum Disorders. (2021, July 21). *What are Evidence-Based Practices?* <https://autismpdc.fpg.unc.edu/evidence-based-practices/>

Organization for Autism Research. (2019) *Life Journey Through Autism: A Parent’s Guide to Research* (2nd edition). Danya International, LLC. <https://researchautism.org/resources/a-parents-guide-to-research/>

Wenn, Lawson. (2021, July 20). *Autism Research: Nothing about Me without Me*. [Webinar]. Autism Research Institute. <https://www.autism.org/category/webinar/research-webinar/>

To learn more about recent research conducted at MAIER, visit our website:
umaine.edu/autisminstitute/2020/08/26/maier-research-highlights/

Access these publications:

Rooks-Ellis, D. L., Jones, B., Sulinski, E., Howorth, S., & Achey, N. (2020) The effectiveness of a brief sexuality education intervention for parents of children with intellectual and developmental disabilities. *American Journal of Sexuality Education*, 1-21. <https://doi.org/10.1080/15546128>.

Rooks-Ellis, D. L., Howorth, S. K., Kunze, M., Boulette, S., & Sulinski, E. (2020). Effects of a parent training using telehealth: Equity and access to early intervention for rural families. *Journal of Childhood, Education, & Society* 1(2), 141-166. <https://doi.org/10.37291/271763>

Questions? Email us at: maineautisminstitute@maine.edu

FAMILY FOCUS

NEWS ESPECIALLY FOR FAMILIES AND CAREGIVERS

Healthy Lifestyles Toolkit now Available Online

The Maine Autism Institute for Education and Research is excited to announce the addition of a new online resource to support individuals and families impacted by autism in developing new healthy habits for a healthy life. The *Healthy Lifestyle Toolkit*, developed by Sara Hunt, a recent UMaine graduate in Child Development & Family Relations, explores a myriad of resources especially suited for parents, caregivers, educators, kids, teens, and adults! Within this online toolkit, you will find direct links to social stories, strategies, training videos, and more pertaining to physical activity, nutrition, sleep, hygiene, and social/emotional wellness.



[View and/or download the *Healthy Lifestyle Toolkit* here!](http://umaine.edu/autisminstitute/resources/maier-resources/toolkits/) (umaine.edu/autisminstitute/resources/maier-resources/)

New Parent Packet available from MAIER

**Free
Parent
Packet**

While we wait for the resumption of in-person family events, conferences, and workshops, MAIER has developed a new Parent Packet to help bridge that gap and assure you know about all the great resources available from MAIER. **MAIER's Parent Packet** includes copies of our print resources such as our *ASD Fact sheet* (good for sharing with family and friends) our *Fire Safety* handout and *Adaptive Sports and Recreation* handout, and our new *Getting Started with Alternative and Augmentative Communication* brochure. We also include up-to-date listings of all the MAIER developed resources available online including educational videos, webinars, and toolkits. If you have not received the *Maine Parent Guide to Autism Spectrum Disorders* booklets yet, we can include this in your packet when requested.

We are sending our Parent Packets to individuals, parents, and caregivers upon request, and will begin mailing packets later in September. Sign up for a MAIER Parent Packet on our [MAIER Resources page](http://umaine.edu/autisminstitute/resources/maier-resources/) (umaine.edu/autisminstitute/resources/maier-resources/) .

Think College Offers Resources for Families and Education Professionals

Are you or your family member on the autism spectrum considering college or currently pursuing college life? Are you an educator supporting students in this endeavor, or a faculty member with a student with autism or other intellectual disabilities (IDD) in your classroom? If you are looking for information, support, training, or resources to guide you in this transition or in using best practices to support college students with IDD, then you should consider checking out [Think College](http://thinkcollege.net/). (thinkcollege.net/)



Think College is a national organization located within the Institute for Community Inclusion at UMass, Boston that offers both online resources and technical support for individuals with IDD, including those on the autism spectrum, and their families, in exploring and/or pursuing the transition to college and college life. Think College also offers individualized technical assistance to individuals and families through their Help Desk and the National Coordinating Center Technical Assistance Providers.

Online resources address questions such as:

- Is College possible?
- How can I prepare and how do I apply?
- Can I afford it?
- How to find the right college, and
- the differences you can expect between college and high school.

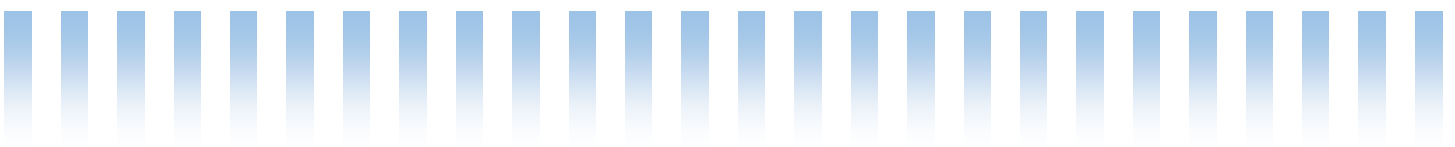
The Think College website also includes an online [College Search Directory](http://thinkcollege.net/college-search) (thinkcollege.net/college-search) on the many college programs across the U.S. for students with intellectual disabilities. Visitors can search by program, location, or keywords.

Educators and college faculty can access *Think College* for technical assistance and online trainings to assist you in supporting students with intellectual disabilities. Training modules and webinars include Universal Design for Learning (UDL), coaching and mentoring college students with IDD, and the roles and responsibilities of campus disability services. Think College staff also offer research summits each year offering an in-depth look at the research related to higher education, employment, and transition.

Think College is an expansive resource for both families and for educators and faculty, and as a national organization is dedicated “to developing, expanding, and improving inclusive higher education options for people with intellectual disability.”

Visit Think College at its website: thinkcollege.net/

Or contact them by phone (617) 287-4300 or email: thinkcollege@umb.edu



FAMILY RESOURCE CENTER

If you have not visited MAIER's Family Resource Center recently, then you may not know that we have re-organized our webpage to highlight MAIER-developed resources and to provide easy access to state and national resources and information to support family life and development. Here is just a sample of the valuable resources listed in our "[Family Life and Developmental Resources](http://umaine.edu/autisminstitute/resources/family-developmental/)" (umaine.edu/autisminstitute/resources/family-developmental/) section of the MAIER Resource Center.

Peer Relationships "[Introducing your child to others](http://www.ocali.org/project/introducing_your_child_to_others)"

(www.ocali.org/project/introducing_your_child_to_others)

This 16 minute video presents a discussion with two parents who have developed positive ways to tell their child's peers about the unique characteristics of the child with autism while emphasizing their child's commonalities with their peers. This video was developed by the Ohio Center for Autism and Low Incidence (OCALI).

Growing Up Together Booklets: These booklets were developed by the Autism Society of America and Indiana Resource Center for Autism (IRCA) to help classmates of a student with an ASD learn about autism. Developed to provide information in a respectful manner and to do so without stigmatizing the student on the autism spectrum.

[Growing Up Together Booklet for Elementary School Children](http://autism-society.org/about-the-autism-society/publications/resource-materials/) and [Growing Up Together: Teens with Autism](http://autism-society.org/about-the-autism-society/publications/resource-materials/) are available on the Autism Society of America's Resource page (autism-society.org/about-the-autism-society/publications/resource-materials/)

Check out our [Family Resource Center](http://umaine.edu/autisminstitute/resources/) (umaine.edu/autisminstitute/resources/) to learn more about all the resources available for families from MAIER.

